

Washington, D.C. – Today, Congressman Joe Sestak (PA – 07) voted for HR 493, The Genetic Information Nondiscrimination Act (GINA) of which he is a cosponsor, and which protects individuals from discrimination in health insurance and employment on the basis of genetic information. The legislation passed by a vote of 414-1. — “I was proud to cosponsor this legislation, as it decreases the potential for discrimination in our society based on data gleaned from genetic information,” said Congressman Sestak. “This alleviates questions of concern from individuals who may be worried that they will be precluded from healthcare coverage or from being hired for certain jobs based solely on genetic information.”

Earlier in the day, the Congressman made a statement about GINA on the House Floor, the text of which follows this release. Further, during the fall 2007 semester he was involved in classroom discussions about GINA for the Genetics and Social Policy class taught by Dr. Ruth Cowan (chair of the History and Sociology of Science Department) at the University of Pennsylvania. At the end of the semester, students from that class submitted a position paper on the policy. The students supported the conclusion of the Congressman that this legislation should be passed.

The first portion of the bill deals with health insurance, and will prevent health insurers from canceling, denying, refusing to renew, or changing the terms or premiums of coverage based solely on a genetic predisposition toward a specific disease. The legislation applies to employer-sponsored group health plans, health insurance issuers in the group and individual markets, Medigap insurance, and state and local non-federal governmental plans.

The Health and Human Services Standards for Privacy of Individually Identifiable Health Information) already protect the use and disclosure of all individually-identifiable health information, including genetic information. However, a permitted ‘use’ of health information under the privacy rules (i.e., a specific item under ‘health care operations’) is underwriting, a practice that is inherently discriminatory. Therefore, this bill expressly bans the use or disclosure of genetic information for purposes of underwriting.

With regard to the privacy provisions established by this legislation, the same enforcement structure and penalties created by the Social Security Act for the HHS privacy standards apply with regard to the privacy protections established for genetic information by this legislation. The genetic privacy provisions are enforced by the HHS Office of Civil Rights.

The second major area covered by this legislation relates to employment discrimination, and extends to employers, unions, employment agencies, and labor-management training programs. Employers, labor organizations, employment agencies, and joint labor-management

committees generally are prohibited from requesting, requiring, or purchasing genetic information about an employee or family member, except for a few legitimate reasons. The purchase of commercially and publicly available documents or inadvertently requesting or requiring family medical history would not violate this title. Under each of these exceptions, however, the genetic information still could not be used or disclosed. Further, the legislation protects applicants or employees of private employers as defined under the Civil Rights Act of 1964, State employees, Federal employees, Congressional employees, and employees as defined in 3 U.S.C. 411(c)0.

Remarks made by Congressman Sestak on the House Floor as prepared for delivery:

*The completion of the Human Genome Project five years ago made it possible to identify specific genes that trigger diseases later in life. However, out of fear of losing their job or their health insurance, many Americans have forgone the potential health benefits of genetic testing. One study by the Genetics and Public Policy Center at Johns Hopkins University found that 90% of the study's respondents were concerned that the results of genetic testing could be used against them. A similar study conducted by Georgetown University discovered that of 332 individuals who had been denied health coverage, twenty-two percent believed it was the result of an identified genetic condition.*

*If Americans fear their genetic information will be used against them by employers and health insurance companies, we risk stifling further scientific advances in genetic based research.*

*In Pennsylvania, where the number one cause of death is heart disease (28%), a lack of research progress means more families will lose loved ones to diseases where advanced genetic based research may offer a cure. It is our duty to ensure that as scientific technology advances, discrimination does not grow with it.*

*Currently, 43 states have recognized the duty of maintaining the privacy of genetic information. However, these state laws vary widely in their scope. Texas, for example, uses a narrow definition of genetic information whereas Virginia uses a broad one. Federal legislation is needed, then, to set a national standard and protect personal genetic information from discriminatory use.*

*Since 1995, every Congress has been presented with genetic nondiscrimination legislation but has failed to pass it into law. Before this body is a measure that the Senate has delivered to us with a resounding vote of confidence (95-0) and the President has guaranteed his support.*

*As President Kennedy noted in 1963, "A journey of a thousand miles must begin with a single step." The Genetic Information Nondiscrimination Act is the first step toward advancing the scientific and health benefits of genetic based research protecting the genetic privacy of Americans. I encourage my fellow members to join me in supporting passage of this legislation.*

*I reserve the balance of my time.*